Adding Prednisone to Zytiga – More Side Effects?

Zytiga (abiraterone acetate)

I have heard a few prostate cancer patients comment that they are worried about taking Zytiga (abiraterone) because they are concerned about the side effects of the 5 mg prednisone (2 x day) which is prescribed with the Zytiga. People who have been on prednisone for other reasons (gout, arthritis, etc) may have had prednisone side effects which might make them hesitate to try Zytiga – just for this reason.

However, when prednisone is given with Zytiga, it's given for a different reason. One of the purposes is to actually LESSEN side effects from the Zytiga treatment. Simply put, Zytiga (abiraterone) can actually lower blood levels of cortisol in many patients, so the prednisone is considered cortisol "replacement", which can help reduce side effects from Zytiga treatment. This is a much different situation than giving prednisone alone for other reasons such as gout or arthritis.

An article in December 2014 of The Oncologist says it this way, "…glucocorticoid compensates for abiraterone-induced reductions in serum cortisol and blocks the compensatory increase in adrenocorticotropic hormone seen with abiraterone.

Consequently, **5 mg prednisone twice daily serves as a glucocorticoid replacement therapy when coadministered with abiraterone acetate…"**

Dr Leonard Gomella also discusses the issue in **this online video**, *"I think you can safely say that low dose of prednisone does not cause any specific corticosteroid toxocity…"*

Since prednisone administration is clearly different than prednisone prescribed for other reasons, talk to your pharmacist if you have any concerns. Zytiga is usually administered through a Specialty Pharmacy, not a retail or neighborhood pharmacy. Talk to a pharmacist at one of these locations if you have any questions. Make sure the information you are working from is correct as you make your ongoing treatment decisions for your prostate cancer.

Also, if you would like to receive a **copy of one of our new brochures called "Ask Your Pharmacist (too…)",** please email PAACT at **paact@paact.help with your request and mailing address.**

(The brochure is completely free,
but donations are always appreciated if possible.)

How Fear Affects Cancer Survivorship – Jesse Gruman PhD, 2013

by JESSIE GRUMAN, PHD | PATIENT

A recent Wall Street Journal article about how post-traumatic stress syndrome can be caused by cancer and stroke brought to mind the variety of responses many people experience in response to cancer diagnosis and treatment. Th e lingering intensity of those responses – physical, psychological, social and behavioral – can affect whether and how we attend to the tasks of survivorship; that is, monitoring and addressing the unique health challenges that follow treatment for cancer.

Sam, a friend of mine, told me that his anxiety is starting to rev up about his annual scan to check for a recurrence of his esophageal cancer. It's early July. His appointment is in mid-September. He doesn't want to go. He will force himself to go. He will worry more each day as the test date approaches.

The sound technician for a recent talk I gave recounted how, 17 years after his radical prostatectomy, he insists on having his PSA tested every six months, despite the one year

interval recommended by the guideline. “From the time the blood is drawn to when I get the results I’m still a wreck. And in between tests, my worry is like a pebble in my shoe. It’s small, but it’s always there.”

Some of us are able to approach our survivorship care as just the next few necessary chores. Others have had enough of the cancer experience by the time we have finished treatment: we refuse to participate in any monitoring or testing at all. Some of us – like Sam – muscle through: constantly surfing the waves of worry.

And some of us take matters into our own hands. Like the sound technician above, we insist on surgery or medication now or we demand more frequent testing than is recommended. We devise our own dietary, physical and mental regimens and employ a range of alternative medicine approaches – sometimes substituting them for standard medical approaches – in an effort to reduce our apprehension and to reclaim some sense that we can control our future.

I wish I had known earlier that a strong emotional response to cancer treatment is fairly common.

I recall becoming nauseous at the prospect of walking into a hospital (any hospital!) and the build-up of crushing fear in the days before getting a simple PAP test. At first these responses kept me far away from any follow-up care. Then when my fear of a recurrence exceeded my fear of testing for a recurrence, I found myself panicking prior to every checkup, every test. I believed these were rational responses to the highly toxic, aggressive treatment and callous care of an adolescent surprised by a diagnosis of Hodgkin’s lymphoma and the threat of impending death at age 19.

I wish I had known earlier that there was no need to suffer so much or so long from these lingering fears.

Talking with others who experience similar anxieties might have made it seem more normal. A behavioral intervention by a mental health professional could have drained some of the anxiety.

As control of pain and nausea become more effective, perhaps fewer of us will experience such responses. But the effect of a cancer treatment affects each of us differently. Increased recognition by our clinicians of its potential impact and help finding effective approaches to accommodating our new reality can help to calm the waves of emotion that get in the way of returning to the lives we love.

Cancer treatment can affect physical, emotional, cognitive, social, behavioral and occupational aspects of our lives. Survivorship care by definition is care of the whole person. It sometimes takes my breath away that my own fear could easily have stood in the way of the discovery and treatment of my four subsequent cancers. I wish I had known earlier how easy it would be to undermine the possibility of benefitting fully both from the treatment I received and the recommended monitoring and testing because I couldn’t see that I needed help with my fear.

Jessie Gruman is the founder and president, Center for Advancing Health. She is the author of Aftershock: What to Do When You or Someone you Love is Diagnosed with a Devastating Diagnosis. She blogs regularly on the Prepared Patient Blog.

The Importance of Belonging to a Support Group, Gene Van Vleet, COO, IPCSC, San Diego CA, 2011

Following the recent consternation provoked by the recommendation of the U.S. Preventive Services Task Force (USPSTF) panel to discontinue PSA testing, it is fitting that we address the benefits provided by support groups in dealing with Prostate Cancer.

Commonly a man visits his general practitioner on an annual basis for a general physical. This can include **bloodwork that includes a PSA test and a digital rectal exam (DRE). Make sure you keep a log of your results.** Too often the patient is not informed of the results, but rather is informed "everything is OK." If the PSA test and/or the DRE is of concern to the physician the patient is referred to an urologist for further diagnosis. All too often the next step is a biopsy. Once a biopsy is performed, the roller coaster of treatment options begins. WAIT A MINUTE!!! What is missing here? Patient knowledge and understanding!

As principal of a highly active support group it is my experience that I am most commonly contacted by patients either after a biopsy or after a relapse following treatment. I can help fill the knowledge gap and **lead men to information with which they can learn to be their own case managers rather than be reliant on physicians' recommendations.** I am by no means a medical professional but I have the knowledge of collective experience to aid men through the confusion of dealing with our troublesome disease. Further, I bring specialists in dealing with our disease to our group meetings to keep us informed of the latest developments without the

restrictions of learning and protocol too often suffered within the medical community.

Let us begin with the myth of the PSA test. It was never intended to be utilized as an indicator of the seriousness of the cancer. Its best value is as a marker to monitor elevation over time. Concerns should develop if the score doubles within a year. Simple logic must be used if the score begins rising. It could be because of an ancillary infection. It could be because the test was performed by a different laboratory. It could be because of strenuous exercise prior to the test. One should first verify the test before proceeding. If the PSA is proved to be validly escalating, be real careful about the usual next step—Biopsy.

There has been significant progress lately in prostate imaging that can analyze the condition of the prostate BEFORE an invasive biopsy is performed. Should such imaging indicate the need, a biopsy can then be performed aided by that imaging. Please, no more random biopsies that may miss the troublesome area! Where do you get these tests? Your support group is a good place to find where such imaging is available in your area.

If you have reached the stage of having a biopsy performed, a Gleason score results, which has been the landmark for determining the seriousness of the cancer. Other tests are arising and being validated that can assist in this determination as well. Your support group will likely know their status or can lead you to sources that will know.

We hear too often of cases where a patient is given treatment without a complete medical check-up. Pity the poor man who saw his urologist because his PSA was rising rapidly. He was given a hormone injection and consequently suffered atrial fibrillation and, later, a mild stroke. His physician failed to check his overall physical condition. Incomplete medical training associated with proper health investigation

before treatment can be a problem.

Once a Gleason score is rendered, too often treatment is implemented before a thorough understanding of the possible effects on the patient's life are achieved. Surgery? Radiation? Cryoablation? HIFU? Hormone Therapy? et al. What a maze of possibilities exist. Get involved with your support group and benefit from their knowledge and experience.

We think one of the major oversights in treatment possibilities is no treatment at all or Active Surveillance (often called Watchful Waiting). Dr. Duke Bahn has quantified those tests that can be monitored by a patient over time in concert with his doctor without undergoing invasive treatment (see PAACT article in March, 2011 issue). An important element of this choice is the mental capacity to overcome a man's natural urge to do something to "cure" the disease. Be careful of that word. When someone uses it, make them define to you what they mean. It might be that they consider you "cured" if you don't experience signs over a much shorter time span than you expect.

If you are faced with making a treatment choice, be sure you develop an understanding of the possible side effects of the chosen treatment. Another unfortunate issue in dealing with prostate cancer is that it is difficult to predict how a patient will react to the treatment. Your physician may cite percentages of success, but there is yet no way to ensure what your experience will be. Be sure to check the experience of the doctor treating you. The most experienced doctor will achieve the best results. And, for sure, seek second opinions from unassociated doctors. This can be difficult because of insurance coverage limitations, but it will be in your best interest. Remember, you are your own case manager. Have confidence that unless you are diagnosed at a late stage the disease is generally slow moving. You have time to assess your treatment possibilities before committing.

Stay involved with your support group. You will find comfort in networking with others to help them as you are being helped. The natural tendency is to be involved through treatment and then disengage. There is value in continuing to stay involved to learn of advances in diagnosis and treatment. It keeps you aware of monitoring your own condition. Too many of the newcomers to our group are experiencing recurrence. Staying abreast of your condition and what is developing in the treatment of the disease will surely give you the opportunity to deal with it successfully. Remember, YOU CAN LIVE WITH PROSTATE CANCER!

www.ipcsg.org • 1-619-890-8447 • Gene@ipcsg.org

Changing Your Lifestyle Can Change Your Genes, Dean Ornish, MD 2011

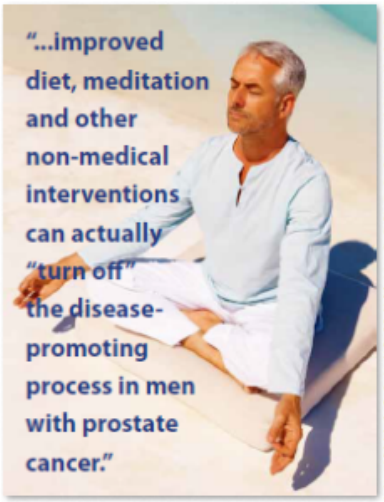
New research shows that improved diet, meditation and other non-medical interventions can actually “turn off” the disease promoting process in men with prostate cancer.

Here’s some very good news: your genes are not your destiny. Earlier this week, my colleagues and I published the first study showing that improved nutrition, stress management techniques, walking, and psychosocial support actually changed the expression of over 500 genes in men with early stage prostate cancer. This study was conducted at the nonprofit Preventive Medicine Research Institute and the University of California, San Francisco in collaboration with Dr. Peter Carroll, Dr. Mark Magbanua, Dr. Chris Haqq, and others.

In this study, published in the Proceedings of the National Academy of Sciences, we studied gene expression in biopsies from 30 men who were diagnosed with low-risk prostate cancer. These men had decided not to undergo conventional treatments such as surgery, radiation, or chemotherapy for reasons unrelated to the study. They had early, small-volume prostate cancer with stable prostate specific antigen (PSA) levels and Gleason scores of six or less, meaning that their tumors were not aggressive.

We biopsied their prostates at the beginning of the study and again three months later, after making comprehensive lifestyle changes. Since these patients did not have conventional treatments during this time, it enabled us to assess the effects of the lifestyle changes on gene expression without confounding interventions such as surgery, radiation, or chemotherapy.

The changes included a plant-based diet (predominant fruits, vegetables, legumes, soy products, and whole grains low in refined carbohydrates), moderate exercise (walking 30 minutes per day), stress management techniques (yoga-based stretching, breathing techniques, meditation, and guided imagery for one hour per day), and participating in a weekly one-hour support group. The diet was supplemented with soy, fish oil (three grams/day), vitamin E (100 units/day), selenium (200 mg/day), and vitamin C (2 grams/day). These lifestyle changes are described more fully in my book, *The Spectrum*.



After three months, we repeated the biopsy and looked at changes in normal tissue within the prostate. We found that many disease-promoting genes (including those associated with cancer, heart disease, and inflammation) were down-regulated or "turned off," whereas protective, disease-preventing genes were up-regulated or "turned on." For example, a set of cancer-promoting oncogenes called RAS was down-regulated in these men. The Selectin E gene (which promotes inflammation and is elevated in breast cancer) was down-regulated. Another gene that suppresses tumor formation called SFRP was up-regulated, thereby reducing the risk of cancer. These genes are the target of many new drugs that are being developed. Clearly, changing lifestyle is less expensive, and the only side-effects are good ones. Dr. Craig Venter's pioneering research is showing that one way to change your genes is to synthesize new ones. Another may be to change your lifestyle.

For the past 31 years, I have directed a series of research studies showing that changes in lifestyle can make a powerful difference in our health and well-being, and how quickly these changes may occur. We showed that comprehensive lifestyle changes may stop or reverse the progression of coronary heart disease, diabetes, hypertension, obesity, hypercholesterolemia, and other chronic conditions. Two years ago, along with Dr. Carroll (Chair of Urology, UCSF) and others who also collaborated on the new gene expression study,

we published the first randomized controlled trial showing that these lifestyle changes may slow, stop, or even reverse the progression of prostate cancer, which may affect breast cancer as well. When we published our earlier studies, we didn't understand many of the mechanisms by which these changes may have occurred. Now, our new study is beginning to provide some insight into what some of these genetic mechanisms may be. Because we looked at normal tissue within the prostate (rather than the prostate tumor cells), it is likely that our findings may be generalized beyond men with prostate cancer. Also, people who are otherwise healthy may not need to make such intensive changes and have a spectrum of choices. We are still trying to understand the full significance of these findings—we've raised more questions than we've answered, and we need larger, longer-term studies—but it's already clear that you may be able to alter, at least to some degree, how your genes are expressed simply by changing your diet and lifestyle.

I find this to be a profoundly hopeful message. Often, I hear people say, "Oh, I've got bad genes, there's nothing I can do about it"—displaying what I call genetic nihilism. Our findings (the first to show the effect of lifestyle changes on any kind of cancer genes) can be an antidote to genetic nihilism and, I hope, motivate people to begin making their own changes. In most cases, our genes are only a predisposition; they are not written in stone. And if we have a strong family history for diseases such as prostate cancer, breast cancer, or heart disease— "bad genes"— then we may need to make bigger changes in lifestyle in order to help prevent or even reverse chronic diseases. In the centuries-old debate about nature vs. nurture, we are learning that nurture affects nature as much as nature affects nurture. It's not all in our genes.

20+ YEAR SURVIVORS, 2013

Letters from Six PC Patients – Fall 2013 Newsletter
(FOR PATIENT CONTACT INFORMATION, PLEASE CALL PAACT AT 616-453-1477)

You asked for input from prostate cancer survivors of twenty years. My experience may be of interest and could convince others that “cancer” is just a word – not a sentence.

In 1991 at age 57, during a routine annual physical my doctor was concerned about a PSA reading of 5.7. A subsequent MRI revealed aggressive tumors in both sides of the prostate gland. I had no previous indication or symptoms such as middle of the night bathroom visits so my immediate reaction was shock/horror.

My G.P referred me to an urologist who gave me a Lupron injection which he said would shrink the tumors and make them easier to remove during surgery which he said would be necessary for me to survive. When I asked him about possible down-side of the radical prostatectomy he warned me that I would be most certainly impotent and incontinent. At that time I had recently married so the shock/horror effect went up two notches!!!

I paid that urologist the $500 for the Lupron injection, wished him a nice day and left in a hurry.

During the next few weeks I spent a lot of time on the phone seeking information from specialists all over the U.S.A. about prostate cancer in general and the possible treatments available. Each one of these doctors insisted that their
specialty, – be it cryosurgery, freezing the tumors,

Palladium seed implants , chemical castration, radical prostatectomy, etc. etc., was the only way to go. I had several conversations with the late and great Lloyd Ney who was enormously helpful and encouraging.

I eventually found a urologist surgeon in St. Petersburg Florida, who advised me that using his nerve sparing technique a radical prostatectomy would not only remove the tumors but there was a good chance that incontinence and impotence might be avoided. At this point I was desperate to do something positive so went ahead with the radical. I just wanted that little suckers out of there!

The surgery went well up to a point. I had no incontinence problems, but aft er three months there was no sign of a return to normal sexual life. We then tried injections directly into the penis, which worked very well, but aft er several months the clinical procedure was so lacking in spontaneity and was causing malformation so that was abandoned.

Finally I accepted the urologist suggestions that a penile implant would be a better solution. This was done almost
two years after my original surgery. The big day finally arrived and both my partner and I were pleased with the results and that has been the case ever since.

My PSA after surgery was 0.01 and has remained at that number since 1991. I test religiously every six months and even though my results are good I always attend the doctor’s office with a slight foreboding.

I have never forgotten the help and advice I received from Lloyd Ney and others at the PAACT, and I try to maintain financial contribution to the funds from time to time. I regularly advise people to be tested as I was and several who have taken my advice had learned that they have the disease

but have been able to take advantage of treatments which were not available to me twenty years ago. I exercise regularly, swim every day and try to keep a healthy diet
PT/Florida

_____-

To whom it may concern,
On page 18 of the summer issue it listed a request for Survivors of 20+ years. I guess I qualify as I started combating
cancer in 1985, Sarcoma. Then Prostate Cancer in 1992 that has been back 9 times. Thanks to Cryo, Brachytherapy, and 6 treatments of TomoTherapy, I am still here. With a lot of praying also!!!!

Medical Treatments:
October 1985–Node/Tumor removal around left Spermatic cord (benign then malignant by AFIP 2 months later)
April 1986–Left orchiectomy (didn't get desired margins – Sarcoma)
May 1986–External Beam Radiation
March 1992–Prostate Cancer determined – Biopsy – Gleason Score 3 + 4 = 7
May 1992–Megace started
October 1992–Radical aborted as it has spread out of capsule
December 7, 1992–Megace stopped and Antineoplastons started (Dr. Burzynski– Houston, TX)
January 16, 1995–Cryoablation of prostate as had lost effectiveness to Antineoplastins
May 25, 1995–Stopped Antineoplastins as PSA = 0
March 1999–Brachytherapy as PSA rising
July/September 2005–TomoTherapy of right lymph node as scan showed tumor there and PSA rising
July 5, 2007–Urostomy – Dr. Andrews – Mayo Clinic
April/May 2008–TomoTherapy of right lymph node as C-11 acetate showed tumor there.
December/January 2010–TomoTherapy of left seminal vesicle as

biopsy showed tumor there
July/August 2011—TomoTherapy of right lymph node as scan showed tumor back
July/August 2012—TomoTherapy of bone in right hip as P/C-11 acetate showed tumor there
November 2012-January 2013—TomoTherapy of tumor just starting in L-4
November 2012-January 2013—TomoTherapy of two lymph nodes as C-11 showed cancer in both
As you can see, I was a test subject in many treatments, however the most important is TomoTherapy.
If you need any more information, just let me know.
RG/Arizona

I will hopefully be a 20 year survivor the end of this year.
WR/New York

The last issue of PAACT's newsletter suggested survivors 20+ years with Prostate Cancer be encouraged to send a note. With a PSA in December 1991 of 50, followed by radical surgery and radiation in January 1992 and a year of Lupron in 2011. I'll be 86 in December, 23 years with Prostate Cancer. I'm still very active.

MC/California

In my journey of Prostate Cancer PAACT has played an important role. I praise GOD for all your help and information, which helped me stand up to my urologist and ask for what I had wanted/learned through PAACT.
My cancer is still under control, diagnosed in 1999.

Yours sincerely,
RN/Missouri

March 1992–PSA 15.3, positive biopsy, age 70
May 1992–Radical prostatectomy
1992-1996–PSA 0 – 0.15
Late 1996 – Mid 1997 PSA 0.39 – 0.54
1997–Started Casodex 50 mg/day PSA to 0.08
In recent years have tried different dosages of generic Casodex: 0, 25, and 50 mg/day, also 50 mg every other day.
1997-2013 PSA minimum 0.02, PSA max 1.00
Last tested on 6-17-2013 PSA was 0.55, present age 91 ½, visit urologist 2 times a year
RH/Indiana